

A comparison of professionals' and patients' understanding of asthma: evidence of emerging dualities?

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Abstract

Despite an increase in the provision of services to patients with asthma, morbidity from the disease remains high. Recent research (outside asthma) has raised the possibility that patients may develop a conceptualisation of illnesses which is not entirely compatible with the prevailing biomedical view. This paper compares the way in which health care professionals and patients with asthma described various aspects of the illness, using an approach which considered the type of knowledge which might be used to construct the respective conceptualisations of asthma. A qualitative method is employed, using focus groups. Eight focus groups were convened, four of professionals and four of patients with asthma. Following the initial data analysis, the results were reviewed linguistically, with particular attention to the use of metaphor.

The health care professionals and patients participating in this study agreed broadly in their explanations of the aetiology and drug treatment of asthma. The data suggest lack of congruence in the development of treatment strategies and locus of control. Health care professionals and patients in this study used linguistically different metaphors to represent the disease: the former more frequently used metaphors evoking on-going processes, the latter visualising the chest (in their use of metaphor) as a static container, emptying and filling throughout the course of the disease. Two commentaries from philosophical and anthropological literature are considered in order to offer theoretical accounts relevant to this interpretation. The data suggest an emerging duality in the approach to treatment plans, in the roles played by professionals and patients with asthma, and in the different types of knowledge used by professionals and patients to construct their respective working models of asthma.

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Introduction

Asthma is a common disease. Its prevalence is increasing, and despite a clearer understanding of its pathogenesis, morbidity and mortality from the disease remain high.^{1–3} Most patients with asthma receive their care in the community, where a large

number of general practices have responded by providing an increasing number of clinics, often led by specialist practice nurses.^{4–5}

Despite this increase in service provision, recent surveys have shown that about half of all asthmatics continue to have night symptoms, and of that group, about half have such symptoms most nights.⁴ There is no good indicator which can accurately predict adverse outcome in asthma.^{6–8} Neither the peak expiratory flow rate (PEFR), symptom scores used in isolation, nor amount of bronchodilator use has been validated as a reliable predictor of outcome.^{9–10}

Thus, the situation is paradoxical: health service provision for asthmatic patients is greater, and effective treatments are available, but morbidity from the disease remains high. A number of factors might contribute to this situation. There is published evidence which suggests low levels of adherence to seemingly logical, rational medical advice, particularly about the prophylactic use of steroids, and considerable dissonance between their recommended and actual use.¹¹ A person's attitude to and beliefs about asthma can influence the way treatments are used.¹² Thirdly, there could be misunderstandings between the doctor or nurse and patient about the nature of asthma or its treatment. A small number of semantic studies have shown how such potentially important differences in conceptualisation might be revealed by the vocabulary used by patients¹³ or by their use of metaphor.^{14–16} Beate *et al* have argued¹⁷ that such dissonance might better be understood by considering theories of knowledge, citing Piaget's distinction between operational and figurative knowledge.^{18–19} The dual taxonomy of knowledge alluded to by Piaget is echoed elsewhere, notably in Toulmin's separation of universal (essentially scientific) and existential (effectively personal, lived) knowledge.²⁰ Michael Polanyi's seminal text, *Personal Knowledge*, deals centrally with the distinction, arguing for a reconciliation between the two epistemologies.²¹

In a consultation about asthma or any other condition, the way in which information is packaged, expressed and exchanged is central. Such information, expressed in words, reflects the speaker's thinking and, in turn, knowledge base. Analysing consultations from this perspective, that is seeking to elicit the knowledge base which constitutes the

bedrock of the exchange might, therefore, shed some light on how the participants think. Are the knowledge bases of the participants in such a consultation the same? If they are different, how can we elicit this, and what difference might that make?

This study set out to explore and compare how doctors and nurses on the one hand, and individuals with asthma on the other, expressed their understanding of various aspects of asthma. We attempted to compare the explanatory constructs of the two groups, to see if these would cast any light upon their respective understanding of how the disease worked, and to see if they influenced the way asthma was managed.

Methods

This paper reports on part of a large quantitative study of asthma, whose aim is to identify predictors of deterioration of asthma. In an introductory part of this study, the initial aim was to seek out and compare patient- and professional-based outcomes of asthma. Both sets of outcomes were then to be identified by analysing focus group data, with two series of focus groups (patient and professional) running in parallel. Focus groups were chosen as the preferred qualitative method because they were considered most likely to give rich data, particularly from patients, by allowing the group interaction to encourage the formation of patient-sensitive outcomes.²² After the first two groups, however, it was obvious that little data about outcomes was emerging from the patient group, while the professionals very quickly rehearsed the well-known “medical” outcomes for the disease. Preliminary field notes of these meetings commented on the vocabulary used by some patients to describe the experience of having asthma, and noted how this contrasted with the conventional biomedical description of the professionals.

The research question therefore changed, in keeping with the heuristic nature of qualitative research.²³ The inquiry then focused on the precise way in which the two sets of participants described various aspects of asthma: the analysis centred on the use of language in their testimony. The research questions became: “Do patients and professionals describe asthma in different ways?” and “What can be inferred from this data about the knowledge base upon which these expressions are constructed?”

The study was convened in the South West of England, with approval from the local ethical committee. Two sets of focus groups were convened in parallel, four comprising professionals (doctors and nurses), and four drawn from patients with asthma. The professional groups comprised one separate group each of specialist doctors, secondary care nurses, general practitioners and practice nurses. Individuals with asthma were identified from general practice disease registers. To obtain a sufficient spread of patients with the type of asthma seen routinely in general practice, the sampling frame was stratified by age, and use of inhaled steroids (which was used as a proxy indication of asthma severity). The age bands were 16–44, and

45–65. Inhaler use was dichotomised as regular (defined as receiving a prescription for a steroid inhaler monthly over a period of twelve months) or infrequent (fewer received steroid inhaler prescriptions). Thus, one group each of young citizens who had received regular or infrequent steroid inhalers was convened, alongside two similar groups of older patients. None of the participants had experienced a hospital admission for asthma within the preceding year.

The groups, lasting 60–90 minutes, were convened between October 1997 and April 1998 according to published guidelines^{24, 25} and were facilitated by a researcher with experience of qualitative research.²⁶ The following questions were explored in each group: What is asthma? What are the treatments of asthma and how do they work/what do they do? What is it like to have asthma, or what must it be like? What are good outcomes of asthma treatment?

Data in the focus groups were recorded by audiotape with additional hand-written notes constituting a contact summary. A two-stage analysis was used. Firstly, a content analysis elicited the frequency with which terms were used in the participants’ descriptions. Then a second-stage analysis identified the key conceptual themes in the data, linking them together in categories where appropriate. Once these categories had been completed, the researchers considered what type of knowledge might have been used in their construction, and also any power relationships suggested by their comparison. The trustworthiness of the coding frames was strengthened by review of an unmarked transcript by two experienced qualitative researchers and by presentation of the initial analysis to participants, who offered their comments on the analysis. Once the data analysis was completed, the initial findings were reviewed by one author (KE), an academic literary scholar, who commented specifically on the use of metaphor.

Results

COMPOSITION OF THE FOCUS GROUPS

Two nurse groups were convened, each consisting of six participants. All the general practice nurses participated in the shared care of asthma. The two doctor groups consisted of seven specialists, ranging from registrar to consultant, and five general practitioners, all of whom were trainers. Between four and seven participants attended each patient focus group. In total twenty-two participants attended the patient groups, nine of whom were men. The age range was 16–44, and 45–65 years. In all the groups, the participants were Caucasian and English-speaking.

Data analysis

WHAT IS ASTHMA?

In the professional groups, the term “inflammation” occurred more frequently than any other term and incorporated the notions of “swelling”, “oedema” and “obstruction”. Less frequently used

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terms were “narrow”, “constrict”, “smaller” and “tight”. The doctors’ groups described a detailed pathophysiological pathway for asthma which included descriptions of “leukotrienes” and “cytokines”. One hospital doctor said: “I mean potentially it involves probably formal components of your inflammatory pathway, so probably certain parts can be switched off ... some are more prominent than others” (hospital doctor).

For the patients, the terms “constrict”, “narrow” and “tight” predominate as descriptors of asthma. “Inflammation” was used less frequently and only once in the group of younger asthmatics using regular inhalers. The descriptions of asthma in these groups tended to be less conventionally biomedical, but obviously made sense to the participants, none of whom were challenged or derided for having idiosyncratic visions of what asthma was. One participant, for example said: “It seems more tight here just above my lungs, and someone’s clenching them. This sounds ridiculous but it feels as if there’s a load of carpet in them”. (younger group, male, regular use of inhalers)

The dominant metaphor in the professional data in this section was of processes, for example “show pictures of swollen airway” (specialist nurse), or in the use of the phrase “path way . . . so probably certain parts can be switched off”. For the patients the dominant metaphor was of containers: “It’s like a windsock” (younger, infrequent use) “Hubbly bubbly pipes,” (younger, frequent use).

WHAT ARE THE TREATMENTS FOR ASTHMA AND HOW DO THEY WORK?

The professional groups identified beta stimulant drugs and corticosteroids as the essential drugs for treating asthma. As one specialist nurse said: “one opens up the airway, the other stops it closing”. The professional groups stressed the prospective benefits of using corticosteroids: “one makes you better at the time, the other keeps you better for tomorrow” (general practitioner). Thus, treatment strategies could or should be planned prospectively. The professional groups saw steroids as central to disease control, but recognised that patients were sometimes apprehensive about using them: “They’re [patients] worried when you say this is a steroid inhaler and you give quite a little spiel about this being quite safe” (general practitioner). Sometimes patients did not fully “understand” their role. Consider this exchange:

(Nurse speaker 3): “It’s quite interesting, they don’t seem to be aware of the significance of their preventer, like you say.”

(Nurse speaker 4) “It’s because they didn’t think they needed it.”

(Nurse speaker 3) “Yes, that’s the commonest thing.”

The patients’ groups identified salbutamol and beclomethasone as the two main treatments. The patients referred to these by their brand names (Ventolin and Becotide respectively) and these

brand names appear in the patients’ remarks reported here. There was a clear consensus about the effect of Ventolin: “The quickest relief. Less than a minute. Straight away” (older female infrequent use). The role of Becotide was less clear. “It’s a medication which soothes” (young female, frequent use). “In the theory, I believe, I think it coats your lungs” (younger male, frequent use).

The patient groups confirmed the professionals’ concerns about apprehension and understanding of steroids. Fear of the use of steroid inhalers was repeatedly described by the patients, who linked the use of Becotide with suppression of disease activity and with a decreased need for regular Ventolin use. The intermittent use of Becotide was a clear theme: “I only take Becotide when I’ve got something happening I can’t possibly miss” (younger female, regular inhaler use). Often, an individual’s decision to use Becotide was based upon a previous experience of it, (and not, as the professionals might have hoped, on its therapeutic rationale). “I take it if I get bad or get a cold ... on to my browns three or four days then it works. All the bad stuff comes towards it and bounces off it or gets eaten possibly. Maybe absorbed” (younger male, frequent inhaler use). This sometimes led individuals to act against medical advice to use Becotide continuously. “When you haven’t got a tight chest you haven’t got asthma, I just forget to take Becotide” (older group, male, infrequent inhaler use). Here, the participants seem to be constructing treatment plans retrospectively, based upon their accumulated experience of asthma.

THE EXPERIENCE OF ASTHMA: WHAT IS IT (OR MUST IT BE) LIKE?

Both the professionals and the patients agreed that asthma was a stigma which could cause embarrassment and restrictions in sporting, and some social, activities. This led some patients, in the view of the professionals, to resist the diagnosis: “They’re not prepared to play the sick role, they deny the diagnosis.” (general practitioner) Teenagers were more likely to do this, perhaps because, “they have no sense of their own mortality do they?” (community nurse). Asthma could be frightening, embarrassing and impair social activities, the professionals suggested.

The patients’ data produced some poignant descriptions of the stigma and embarrassment attached (in their view) to having asthma. Sometimes, patients felt they should use their inhalers out of sight. “I’d sneak out on me (*sic*) own to use my inhalers so nobody could see it.” (older male, infrequent use of inhaler) “I go to the loo” [to use inhalers] (younger male, frequent inhaler use). One individual reported: “Asthmatics at school were wimps. I don’t want to be thought of as an invalid,” (older male, infrequent inhaler use).

HOW DO YOU MANAGE (YOUR) ASTHMA?

Within the professionals’ data, a clear responsibility for educating patients about asthma emerged, with nurses seen as key players. Within this educational

Table 1

Theme	Professional group	Patient group
What is asthma? Content analysis, main descriptors	“Inflammation”, “swelling”, “oedema”, “obstruction”	“Constrict”, “narrow”, “tight”
Dominant metaphor	Process	Container
Treatment perspective	Prospective	Retrospective
Managing asthma	Prior professional responsibility assumed, and then transferred	Patient as experts : “I know my asthma better than anybody”
Locus of control	Operational (Piaget)	Figurative (Piaget)
Taxonomy of knowledge used in constructing the model of asthma	Universal (Toulmin)	Existential (Toulmin)

theme, the nurses described a relationship between professionals and patients which most closely resembled a teacher-pupil relationship. For example, when one professional commented on some patients refusing “to go to classes”, (community nurse) the contact summary confirmed a group consensus. Within this teacher-pupil relationship, the professional groups perceived the need to keep clinical messages “simple”: “I don’t mean to be rude, but I mean you need to make it as basic as possible,” (specialist nurse).

In one of the early patient groups an individual spontaneously reported: “I think you can generally advise yourself... . I think I can advise myself better.” (younger male, frequent inhaler use). The facilitator tested this piece of testimony on that group and subsequent groups, and the contact summary confirms that there was a strong feeling among the individuals that they were experts in their own disease. “I know my asthma better than anybody.” (older female, frequent inhaler use). This data evokes a tension in roles: the professionals with their desire to act as teachers, and the patients’ sometimes distressing descriptions of their own expertise.

A subsidiary theme within this category suggested that patients may be the victims of their own actions. “Some have really brought it upon themselves because they smoke,” (practice nurse). Referring to patients whose asthma was poorly controlled one practice nurse commented: “you have allowed it to take over.” Many of the participants agreed that their asthma was not always well controlled. Some blamed themselves when they experienced exacerbations of asthma “I feel guilty getting bad and having to go to the doctor quick—to get a nebuliser—you know. I hang on and hang on.” (younger female, infrequent inhaler use). The concept of guilt associated with exacerbations was vivid, for example, when the deterioration occurred at a friend’s house thus causing inconvenience). Some admitted not wanting to interrupt their normal planned activities, or assumed that the deterioration they were experiencing would be transitory.

By contrast, discussion of the locus of control in asthma by the professional group suggested prior ownership of responsibility for the disease by the professional before returning or yielding it back to the patient. “We have to put control onto the person themselves (*sic*) to manage it,” commented one practice nurse, a proposition which could be tricky

with “difficult patients, where you have to allow them to take responsibility”.

WHAT DO YOU THINK ARE GOOD OUTCOME MEASURES FOR THE TREATMENT OF ASTHMA?

The specialist groups easily rehearsed the conventional outcome measures for asthma: absence of wheeze, absence of cough, absence of early morning waking, ability to perform exercise, and not having to take time off work.

The patient groups did not specifically identify these conventional outcome measures in detail. Rather, they reported that they did not want to be embarrassed or fearful of their asthma, nor inconvenienced by it. “I want a totally normal life” (younger female, infrequent inhaler use), said one group member. “Just not to have to use inhalers,” (younger male, infrequent inhaler use) commented another. On the whole, individuals in these citizen groups felt they could sense any deterioration in symptoms themselves. Little was added to that impression by recording the peak flow rate. “I only do peak flow rate to see the nurse or the doctor.” (older participant, frequent use of inhaler).

We summarise the main points from these results in table 1.

Discussion

There are a number of drawbacks to this study. Firstly, focus groups, while appropriate initially, when differences in outcome were being explored, are probably not the best way to elicit differences in the use of language. We accept this, but argue that within these focus group, the patients were able to put forward ideas in their own words which the group could evaluate—for example by criticising a particularly peculiar vision of asthma. The field notes bear this out: the focus groups actually were “permission-giving” fora in which participants felt free to offer their private views when they saw that others were willing so to do. Secondly, the participants in these citizen groups could all be said to have accepted their diagnosis: Adams *et al* have written about the important group of asthmatics who deny their disease.²⁷ One could speculate that different data might have emerged from groups of such participants. Finally, no particular themes emerged to distinguish the understanding of asthma as a function either of age or inhaler use, the two strata upon which the groups were convened. However, several key ideas which emerged from our

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data fit with previous published work in this area, for example the notion of patients as experts, and the stigma attached to having asthma.²⁸

In summary, this study has addressed two questions: Do professionals and patients describe asthma in different ways, and what can be inferred from this data about the knowledge base upon which these expressions are constructed? We address each of these in turn.

DO PROFESSIONALS AND PATIENTS DESCRIBE ASTHMA IN DIFFERENT WAYS?

The data show clear areas of congruence or shared understanding between the professionals and the patients: both groups broadly agreed on the treatments for asthma, and agreed that there were difficulties in the use of inhaled steroids. Within the set of data describing the role of steroids, a paradox begins to emerge, elicited particularly by a doctor's use of the phrase "keeps you better for tomorrow". In general, the data suggest that the professionals stressed the prospective benefits from using steroids. Patient participants evaluated the efficacy of the inhaled steroid in the context of their accumulated personal experience of it—ie retrospectively—and judged its value accordingly. We interpret this as evidence of a divergence or "duality" in respect of the two perspectives upon which their respective treatment strategies are based.

A second paradox emerges in the data describing expertise in asthma, and locus of control. A clear theme in the patients' data suggests a developing personal expertise in asthma management, allowing the patient "to advise myself better", or "know my asthma better than anybody". The health care professionals on the other hand, clearly feel a sense of responsibility for managing asthma for patients: they adopt the role of teacher and assume initial responsibility for the disease before deciding, at times, to "put control onto the person". We suggest this might represent a further duality in relation to disease management.

We postulate that these differences in approach to treatment and management imply deeper differences in the ways the two groups think about asthma. That these differences are linked to language is supported by the different metaphors—process versus container noted in their descriptions of the disease. Such a disparity between doctors and patients in the use of metaphor when discussing asthma has recently been highlighted,¹³ and reflects an increasing interest in language-based medical research.²⁹

WHAT CAN BE INFERRED FROM THIS DATA ABOUT THE KNOWLEDGE BASE UPON WHICH THESE EXPRESSIONS ARE CONSTRUCTED?

This analysis supports the possibility that there is an epistemological difference between doctors and patients in this context. While some might consider this a truism, that the two have different perspectives, we postulate that this may reflect a more profound distinction, namely that each group draws on different types of knowledge to construct the

thoughts and words with which they describe asthma. The possibility of such a distinction is recognised in the philosophical literature. We can begin to understand these differences by drawing on Piaget's distinction between figurative and operational knowledge, referred to earlier.¹⁸ The professionals, who in general do not have direct experience of actually having asthma, use their theoretically based knowledge to participate in the dialogue. Piaget would call this type of knowledge operational. The patients' knowledge arises out of direct lived experience, which Piaget classes as figurative. Although these categories are not meant to be mutually exclusive, it does introduce the possibility, arising from the data, that the two groups construe asthma in slightly different ways. Using Toulmin's taxonomy,²⁰ the professionals draw on universal knowledge, while their patient counterparts use an "existential knowledge base". Again, Byron Good argues that medicine reconstitutes the familiar human body as "the medical body": doctors see the human body in medicine's own way, with medicine's gaze, and use a particular vocabulary to describe it.^{30,31} Within medicine, Good argues, the human body is "newly constituted as a medical body, quite distinct from the bodies with which we interact in everyday life".³⁰ We argue that in this data set, the words, constructs, and strategies described by the two groups reflect the epistemological dualities postulated by these commentators.

What are the implications of such a view? Firstly, it underlines the relevance of the philosophical literature to everyday clinical practice. Secondly, it demands a "post-modern" view of illness in which the biomedical component is inextricably intertwined with the cultural, societal aspects: no one component is more robust, more real or more relevant. The experience of illness occurs at their intersection.^{32,33} Thirdly, it introduces a potential impediment to implementation: if consultations cannot be seen as literally shared dialogues, but rather as a kind of fluid elusive exchange of extracts from differing knowledge bases, the process of implementation may not be a simple linear process (that is just explaining and handing over information), but may be more complex.

Further research in this area would refine the analytical approach in this study by examining video recordings of live consultations, and interviewing the participants to find out precisely what they were thinking when they made a contribution. Language-based medical research should be encouraged to explore the epistemological basis of patients' and health care professionals' interactions during consultations.

Authors' note

Drs Halpin and Stead had the original idea for the project, assisted in its planning and commented on the article through each of the drafts. Dr Sweeney carried out all the focus groups work and the first level data analysis. Dr Edwards carried out the

analysis of the use of metaphor, and commented on the successive drafts of the paper.

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